

## Burden on Caregivers of Patients with Schizophrenia and Related Factors

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### ABSTRACT

**Introduction:** Caregivers of patients with schizophrenia are under the burden of continuous and difficult processes. Determination of the factors related to caregiver burden in schizophrenia may help find strategies to decrease the burden. This study aimed at investigating the factors associated with caregiver burden among relatives of patients with schizophrenia.

**Methods:** Eighty-eight caregivers of patients under treatment for schizophrenia for at least 1 year were included in the study. The Zarit Caregiver Burden Interview was used for the assessment of caregiver burden. Sociodemographical data, the level of knowledge about schizophrenia, clinical impression scale, and global assessment of functioning were used to evaluate the related factors.

**Results:** Caregiver burden was negatively correlated with income level and functionality of the patient and was positively correlated with the age of the caregiver, the daily time spent with the patient, and

the number of hospitalizations of the patient ( $p<0.05$ ). There was no significant correlation between the caregivers' knowledge about schizophrenia and caregiver burden ( $p<0.05$ ). Living in the same house with the patient was a positive predictor, whereas functionality and income level of the patient and education level of the caregiver were negative predictors ( $p<0.05$ ).

**Conclusion:** This study highlighted the importance of setting targets for improving the functionality of patients in the design and implementation of rehabilitation and support programs for patients with schizophrenia. Additionally, providing higher income for patients, creating conditions for an independent life, and increasing incentives for younger caregivers with a higher educational level may help decrease caregiver burden.

**Keywords:** Schizophrenia, family, caregiver, caregiver burden, functioning, knowledge about illness

### INTRODUCTION

Schizophrenia is a chronic disease that results in serious disability; it concerns not only the patients themselves but also their family members who assume their care. The World Federation of Mental Health has assessed the burden of those providing care to patients with chronic diseases as a global problem and has announced that caring for these patients requires continuous energy, knowledge, empathy, and economic power and influences daily living to a large extent. While attempting to establish a balance between their jobs, families, and patient care, caregivers usually neglect their own physical and mental health (1).

The caregiver burden caused by schizophrenia is evaluated in a multidimensional way. The negative effects of persons with a serious mental illness on their family members have been explored since the 1950s, and the term "caregiver burden" began to be used in the 1970s. The scope of this concept was broadened after the 1980s. The "caregiver burden" concept that is widely accepted includes all of the physical, mental, social, and economic problems experienced by the relatives of an individual with a chronic mental disease (2).

The factors affecting the burden on caregivers can be related to the patient but can also be related to the caregivers themselves. The World Federation of Mental Health estimates that 80% of the caregivers in the world are female. They can be the spouse, mother, or daughter of the patient. Studies have shown that women who have a patient they are liable to look after have 6 times more depressive and anxiety symptoms than those who have no such liability (1,2). Studies have shown that factors influencing the caregiver burden include male sex of the patient, youth, severity of the disease, cultural factors, stigma (3), duration of the disease, and disability (4). Studies exploring the relationship between economic condition and caregiver burden have shown that a lower socioeconomic level is associated with increased caregiver burden (5). These studies have also stressed the importance of caregiver age, education level, and time spent with the patient in determining the caregiver burden (1,6). Some studies have demonstrated that caregivers usually do not have the knowledge and competence necessary for providing care to a person with a chronic mental illness; many psychoeducation programs have been developed to intervene in this situation (7,8).



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The functioning and general condition of the patients with schizophrenia being looked after may also affect caregiver burden. It is agreed today that when assessing the prognosis of schizophrenia, remission of symptoms and functioning are not the same, and functioning should be investigated as a separate concept (9). A common opinion on the effect of a patient's symptom clusters on caregiver burden has not yet been established. Studies evaluating the relationship between a patient's functioning and illness burden have shown that functioning is an important determinant for the burden (10).

Countries and institutions implement social support programs and educational programs with various contents for both patients and their families along with programs to improve patients' functioning (11,12). Examples of these may include day hospitals, sheltered employment, social skills training, group therapies, family therapies, and assertive community treatments. Establishing a balance between programs for improving patient functioning and psychoeducation programs is important for the efficient use of time and economic resources (13). When conducting programs for those with serious mental illnesses, setting appropriate targets and identifying the ways to achieve such targets is invaluable for the patients and their families in reaching the desired goals (14).

Some previous studies have explored the relationship between caregivers' knowledge of the disease and caregiver burden. Although some sources argue that caregiver burden will decrease as the caregivers' level of knowledge on the disease increases (15,16), there are also studies showing that family burden increases as the level of knowledge of the disease increases (17). When deciding on the roadmap in the process of preparing support programs for patients and their families, it is important to know the factors associated with caregiver burden. Thus, the primary goals to be dealt with first can be identified. The present study aimed at assessing how caregiver burden relates to the patient families' knowledge about schizophrenia, the functioning of the patient, and the clinical condition of the patient.

## METHODS

This study was conducted among patients who were diagnosed with schizophrenia according to the DSM-IV (18) and have been treated at the Community Mental Health Centers (CMHC) in Derince and Sakarya along with their family members who have been providing care to them. Approval was obtained for the study from the Ethics Committee of Koçaeli Derince Training and Research Hospital. Written consents were obtained from the patients and their family members who agreed to participate in the study. The patients were diagnosed through clinical interviews, and the scales were administered to those who volunteered to participate in the study and their family members.

### Sampling

#### Patients

Patients aged between 18 and 65 years who have been treated for schizophrenia for at least the last year, who were not in schizophrenic episodes during the study, and who had no diagnosis of an additional organic disease or intellectual disability were included.

#### Caregivers

As caregivers, we included in this study those family members who assist the patient in their daily functions, performing their medical monitoring and treatment, and meeting their needs and who look after the patient as priority work but who do not perform this work as a professional job (19). Only one caregiver who has the primary responsibility of the patient was included in the study for each patient. The caregivers were selected

from those aged between 18 and 65 years who did not have any intellectual disability or any disease that could affect their cognitive or mental functions. Some of the patients had more than one caregiver, in which case one caregiver was selected randomly.

**Monthly per capita income:** This was obtained by dividing the total monthly income received by the household by the number of persons living in the household.

**Patient's monthly income:** This was considered to be the monthly income received and owned by the patient (by working or with government support).

### Scales Administered to the Patients

**Clinical Global Impression (CGI) Scale:** This is a scale used to assess the severity, improvement rate, and medication side effects of psychiatric disorders. The illness severity subscale was used in this study. The scale for the severity of illness refers to the clinician's global impression of the patient and is scored between 1 and 7. The scale scores rise as the severity of illness increases (20).

**Global Assessment of Functioning (GAF):** This scale helps monitor the clinical progress of an individual in its general framework using a single measurement. With the GAF scale, which is structured in line with the DSM-IV, the patient's psychological, social, and occupational functioning is assessed. The scale involves a general rating of a person's functioning at that moment or in the past by a clinician who gives points between 1 and 100 (18).

### Scales Administered to Caregivers

**Demographic data form:** This form contains questions relating to the patient's age, marital status, education, income status, whether there are any other individuals with disabilities and/or psychotic disorders in the family, and time spent with the patient.

**Illness information document (IID):** This document was prepared by the study team by making use of a document that had been previously used by Yıldız et al. (21); it consists of 20 items regarding the definition, etiology, treatment, and clinical prognosis of schizophrenia. Some of the items give right and some others give wrong information about the illness, and the participants are expected to mark the items as correct or incorrect. Higher scores indicate a higher (correct) level of knowledge. Each correct response of a family member is scored 1, and each incorrect response is scored 0. Scores vary between 0 and 20.

**Zarit Caregiver Burden Interview (ZBI):** This interview was developed by Zarit et al. (22) in 1980. It is used to assess the stress experienced by caregivers who look after an individual or older person in need of care. The scale consists of 22 statements reflecting the effect of providing care on the individual's life and is scored between 0 and 66. The items included in the scale generally concern social and emotional areas, and higher scale scores indicate higher levels of stress being experienced. The scale was tested for validity and reliability in Turkey by Özlü et al. (23)

### Statistical Analysis

The data were analyzed by the Statistical Package for the Social Sciences (SPSS Inc; Chicago, IL, USA) 17.0 statistical program. To compare the mean values of linear variables, the Student's t-test was used for the groups with a standard distribution and the Mann-Whitney U-test for those that did not have a standard distribution. The one-way analysis of variance (ANOVA) test was used to compare caregiver burden in more

than two independent groups. The chi-square test was used to compare categorical variables. The Pearson's correlation analysis was used for correlation analyses and the linear regression analysis for identifying the predictors.

## RESULTS

**General data:** The study included 88 patients and 88 family members who looked after these patients.

**General data on patients:** Sixty-seven (76.1%) of the patients who participated in the study were male. Seventeen (19.3%) of the patients were currently married, 57 (64.8%) were never married, 14 (15.9%) were either separated from their spouses or divorced, and 27 (30.7%) had children. The general data on the patients are summarized in Table 1.

**Table 1.** Characteristics of patients included in the study

Patient (n=88)	Mean±standard deviation	Range
Age	39.27±11.70	19-65
Years of education	8.29±3.63	0-18
Duration of illness (years)	15.79±9.18	2-40
Number of hospitalizations	3.40±4.38	0-20
Time spent in the hospital (days in total)	94.54±128.16	0-775
CGI score	5.10±0.96	3-7
GAF score	36.82±11.12	15-65
Monthly income (TL)*	457.13±456.86	0-2000
*Person's own income. CGI: Clinical Global Impression Scale; GAF: Global Assessment of Functioning		

**Table 2.** Characteristics of caregivers

Caregiver (n=88)	Mean±standard deviation	Range
Age	49.68±12.47	22-65
Years of education	7.46±4.11	0-16
Time spent with the patient in the same house (years) (n=80)	19.70±14.15	0-48
Time spent with the patient during the day (hours)	14.87±8.33	1-24
Per capita income*	460.19±211.68	0-1200
IID score	8.97±2.82	0-15
Zarit Caregiver Burden score	54.76±16.58	27-93
*Calculated by dividing the total household income by the number of people living in the same house. IID: Illness Information Document		

**Data on caregivers:** Fifty-seven (64.8%) of the family members included in the study were female. Of them, 47 (53.4%) were the patient's mother or father (28 mothers and 19 fathers), 22 (25%) were the patient's siblings, 6 (6.8%) were the patient's children, 7 (8.0%) were the patient's spouses, and the remaining 6 (6.8%) were their second-degree relatives. Overall, 31.8% of the family members had additional physical illnesses, such as diabetes mellitus, hypertension, hyperlipidemia, migraine, and rheumatic diseases. The general data on family members are summarized in Table 2.

When the caregiver burden scores of those who had another person with a psychotic disorder in their family (n=31), those who had a person with a disability due to a reason other than a psychotic disorder in their family (n=13), those whose patient under their care attempted suicide (n=25), those who had an additional physical disease (n=28), and those who had a history of exposure to physical violence (n=47) were compared to the caregiver burden scores of those who did not have such conditions, no significant difference was found (p>0.05).

Seventy-one of the caregivers were living in the same house with the patient. When their ZBI scores were compared, the caregiver burden scores of those living in the same house were found to be significantly higher than those of caregivers who did not (p=0.027).

When the employment statuses of the patients were assessed, it was found that 11 of the patients worked actively in a paid job, 32 did not work but had an income in the form of pension or disability allowance, and 25 were not employed anywhere and had no income. When these groups were compared in terms of caregiver burden scores using the one-way ANOVA test, no significant difference was found between the groups (p>0.05).

A Pearson correlation analysis was performed to assess the relationship of caregiver burden with the linear variables that show the demographic characteristics of the patient and their family members and the knowledge level of the caregiver. The results are given in Table 3 and Table 4. According to these results, caregiver burden is negatively correlated with the patient's functioning and income levels and positively correlated with the age of the family member, daily time spent with the patient, number of hospitalizations, duration of living in the same house, and years of education of the caregiver.

## Regression Model

To assess the variables that serve as predictors for caregiver burden, a linear regression model was established with the parameters that showed significant relationships in the correlation analyses. The model involved the independent variables of the patient's functioning level, number of hospitalizations, time spent by the family member with the patient in the same house, daily time spent with the patient, monthly income of the patient, years of education of the caregiver, and the caregiver's age, as well as the dependent variable of caregiver burden; this model showed that the time spent by the family member with the patient in the same house was a

**Table 3.** Correlation analysis of caregiver burden and patient data

	GAF	Number of hospitalizations	Patient's years of education	Patient's age	CGIS	Duration of illness	Days stayed in the hospital	Patient's monthly income	
Caregiver burden	-0.411	0.258	-0.191	-0.152	0.155	-0.142	-0.085	-0.230	r
	0.000	0.017	0.081	0.158	0.161	0.186	0.458	0.031	p

GAF: Global Assessment of Functioning; CGIS: Clinical Global Impression Scale; r: Pearson correlation coefficient; p: significance

**Table 4.** Correlation analysis of caregiver burden and caregiver characteristics

	Time spent in the same house	Caregiver's years of education	Caregiver age	Daily time spent with the patient	IID level	Per capita income	
Caregiver burden	0.482	-0.338	0.335	0.230	0.056	0.42	r
	0.000	0.001	0.002	0.035	0.607	0.698	p

IID: Illness information document score; r: Pearson correlation coefficient; p: significance

**Table 5.** Linear regression analysis of factors predicting caregiver burden

	Beta	t	p
Time spent in the same house	0.384	3.359	0.001
GAF	-0.250	-2.819	0.007
Caregiver's years of education	-0.242	-2.258	0.028
Patient's monthly income	-0.224	-2.258	0.028
Number of hospitalizations	0.146	1.618	0.111
Caregiver's age	0.074	0.639	0.526
Daily time spent with the patient	-0.031	-0.294	0.770

GAF: Global Assessment of Functioning Scale

burden increasing (positive) predictor, whereas the patient's functioning, the caregiver's years (duration) of education, and the patient's monthly income were negative predictors ( $p=0.000$ ) (Table 5). Because no significant relationship was found with the family member's level of knowledge on the illness, it was not included in the regression model.

## DISCUSSION

This study investigated the factors related to the caregiver burden of those providing care to patients with schizophrenia. The factors predicting caregiver burden in this study were the patient's functioning, patient's monthly income, caregiver's years of education, and time spent by the caregiver with the patient in the same house. The caregiver's age, daily time spent with the patient, and number of patient hospitalizations were also found to be correlated with caregiver burden.

The present study showed that the patient's functioning was a significant predictor for caregiver burden. A previous study conducted by Danacı et al. (24) demonstrated that the patient's social functioning was directly correlated with the family's functioning. In another study by Gülseren et al. (25), the components relating to the patient's functioning were shown to predict caregiver burden. A study conducted within the scope of CATIE also showed that the patient's functioning was among the significant predictors for caregiver burden (10). Our study emphasized the importance of the patient's functioning in particular among the factors predicting caregiver burden.

We observed in the present study that as the patient's monthly income decreased, caregiver burden increased. Although no significance was found in relation to whether the patient was employed or unemployed, the patient's income level was found to be significant. Even if the patients participating in this study did not work at a regular job, most of the patients regularly attended a CMHC. Again, the daily time spent with the patient is significant according to this study. These outcomes show that reducing the time spent with the caregiver, as in the case when the patient leaves home during the day, and a fair income for the patient are important factors in decreasing caregiver burden. However, looking at the general Turkish average for the family members who participated in the study, the monthly per capita income is below the poverty limit (26). The

data on low income levels show that governments should review their policies for supporting caregivers. Many countries worldwide remain inadequate in providing the necessary economic support to patients with schizophrenia and their families (1). Poverty may involve restrictions due to increased perception of burden as well as in many areas, such as access to health services in the process of monitoring and treating the illness, access to other social and recreational facilities, meeting basic needs, and unification with society (3). All these restrictions can explain the increase in caregiver burden.

It has been shown in the previous studies on caregiver burden that mostly females assume the care of patients (6). For example, 58% of caregivers are women in the United Kingdom (27). Studies in Asia have reported that nearly 70% of caregivers are women (28,29). Female caregivers also constituted the majority in our study. This information is important for understanding the needs of female caregivers and providing support to them. Ways of engaging more males in assuming this stressful and burdensome duty should be explored.

Studies conducted in Asian countries show that caregiver burden increases with advancing age of the caregiver, whereas it decreases with age in Mexico and America (1). Cultural factors may also play a role in this issue. Similar to Asian countries, caregiver burden increased together with the age of the caregiver in our study. According to our observations, older caregivers seemed to accept the current condition and chronic progress of their patients, and they were more worried about how their patients would receive care after they passed away. This point should be the subject of a separate investigation.

Alongside the age of the caregivers, the present study also assessed how their level of education related to caregiver burden. Although there are previous studies showing that as the education level of the family member increases, caregiver burden decreases, some recent studies have also produced results contrary to this (30). We also found in our study that as the education level of the caregiver increased, caregiver burden decreased. This suggests that younger and better educated persons would feel less caregiver burden when providing care to patients with schizophrenia.

The other two interrelated factors affecting caregiver burden are the time spent with the patient in the same house and the time spent by the family member with the patient during the day. According to the results of our study, family members seem to be living in the same house with the patient and spending approximately 14–15 h with the patient daily; the total time spent with the patient is associated with caregiver burden. This result is similar to those of previous studies (6,31), and it suggests that when patients have an occupation that would make them leave home during the day or they are provided with facilities that would enable them to live independently, this could also be useful in terms of caregiver burden.

From the patient-related factors, the number of hospitalizations of the patient had a positive association with caregiver burden. In a previous study by Gülseren et al. (25) with 237 caregivers, they found that the dura-

tion of the illness and number of hospitalizations had positive associations with caregiver burden. No correlation was found in this study between the severity of the patient's clinical condition in that period and caregiver burden; however, its relationship with the number of hospitalizations was found to be significant. This can indicate that caregiver burden is associated more with the long-term progress of the disease rather than its momentary progress; although they were not in agreement on symptom clusters, previous studies have shown that the severity of symptoms increases caregiver burden (25,30,32).

Some results in our study were not found to be statistically significant, although their relationship with caregiver burden has been demonstrated in previous studies. For instance, although previous studies have shown that there is a correlation between the patient's age and gender and caregiver burden (6,25), we did not find any significant relationship.

Another topic where we did not find any significant correlation with caregiver burden was the caregiver's level of knowledge about the illness. The caregivers' level of knowledge about the illness was measured in its natural environment without any interventions, and more than half of the caregivers could not give the right answers to even half of the questions. Nevertheless, no significant correlation was found in the analyses conducted to assess the relationship of the caregivers' level of knowledge about the illness with burden. This outcome is actually open to debate. Although some sources argue that when the caregivers' level of knowledge about the illness increases, then caregiver burden will decrease (15,16). There are also studies showing that as the level of knowledge about the illness increases, family burden also increases (18). There are many studies stressing the importance and usefulness of psychoeducation programs (33), and psychoeducation groups for families have become the core of most rehabilitation programs (8). Many studies showing the importance of psycho education have demonstrated that after organizing education groups for patients and increasing the level of knowledge of family members, their burden decreases (15,33,34). The results of this study suggest that the level of knowledge about the illness for a caregiver alone is not sufficient in reducing caregiver burden; additionally, psychoeducation programs should include the teaching of coping strategies for the illness and its consequences.

The most important limitation of this study is that its sample size was small. A larger sample would probably reveal sufficient data for generalization of the results. Another limitation of the study is the random selection of the caregivers of the patients who had more than one caregiver so that the sampling of the study was not homogenous. There should be a difference between the caregiver burden of caregivers who give care alone or with the help of another caregiver. This study did not evaluate the relationship between the number of the caregivers and the burden of caregiving; therefore, this is a topic that should be evaluated in future.

Despite its limitations, we believe that this study presents two targets that can be addressed immediately in the short run to decrease the burden on caregivers of patients with schizophrenia: developing rehabilitation programs to improve functioning of schizophrenic patients and improving the income level of these patients. Moreover, issues to be kept in the agenda should include day hospitals to reduce the time patients and their caregivers spend together, sheltered employment, and provision of professional care that would help younger and more educated persons engage in the work of providing care.

In conclusion, it seems important to emphasize interventions for increasing patient functioning in treatment and rehabilitation programs for pa-

tients with schizophrenia and their families and to increase the monthly allowances paid to patients. Another topic to be discussed is attracting younger and better educated professionals to the work of providing care. Developing and proliferating programs to reduce the time spent by caregivers with their patients also appears to be important.

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